

MassCARE News

Spring 2001



Fernanda Gudino-Valentin
Coordinator of Family Support Initiatives

For the most of the past five years, I have had the opportunity to work closely with all of you, in many ways, surrounding many issues and concerns. Over that time, I have grown to respect and appreciate the creativity, ingenuity and dedication that you all bring to this program.

This issue of our newsletter is dedicated to all of you who work hard every day with your children and family, for you who find time out of your busy schedule to attend meetings, support groups and still find time to get involved on different levels of our program.

Since the last MassCARE news was published, the Family Advisory Network (FAN) has had many achievements. I can not forget our visit to Capitol Hill last year - what a success! We made sure our voices and our children's voices were heard by the policymakers. We continue the FAN meetings despite changes and adjustments. The Retreat and Family Networking Day were just the time that we needed to relax and support each other.

What we do day after day does make a difference for a better tomorrow without stigma and pressure for our children.

I can't forget those who are now gone, those who have touched our lives in many ways. I just want you all to know that all your efforts and dedication have helped us continue doing what we have to do and what needs to be done with character, grace and dignity. Your efforts and dedication are appreciated.

As you may know, MassCARE has worked hard over the years to adjust to changes. But we still continue to provide services to families throughout the state. I am very happy to present this newsletter with on-going columns including *'Meet the Staff'*, in this edition we feature an interview with our new Program Director. *MassCARE Milestones* is our way to recognize the achievements of MassCARE participants and staff and say thank you for what you do. What the *Fathers* have to say about *their* group is a must read article. You can also read about the experience of an HIV affected teen in the *Teen Talk* column. Other features include program updates and group schedules from MassCARE sites, *Nutrition News* from Kathy Cunningham of the Department of Public Health, plus much more!

Let me close by expressing my deepest gratitude to all the contributors for their articles.

I hope you enjoy this issue of our new and renovated newsletter.

Meet the MassCARE Staff



Hayley Arnett interviewed Donna Shecrallah, the MassCARE Program Director for this issue of MassCARE News.

Donna has a Masters Degree in Public Administration (MPA) with a concentration in Health Care and has been involved in the HIV/AIDS field since 1987 when she was Director of Home Health Care Service for a non-profit agency in Boston. In 1991, Donna went to work for the Boston Public Health Commission and her focus there was implementation and allocation for the new federally funded Ryan White Title I CARE Act monies that had come into Boston. After working with the Title I CARE Act for 7 years Donna briefly went back to home health care. However, when the opportunity arose to apply for the Director of MassCARE, she applied, was hired, and began last May. She is married, the parent of two girls, Katie who is 11 and Diana who is 9. She loves to read mystery novels and spend time by the ocean with her family and friends.

When Donna was asked what attracted her to this position and what she finds most satisfying she responded, “the attraction was the diversity of each program model across the five MassCARE community based sites. This diversity is the program’s strength because the services meet the needs of the clients in that area.

There are many satisfying parts of my position as director, especially knowing that these federal funds support both people infected with HIV as well as their affected family members. Since I have been here these past nine months I feel fortunate to be part of this strong, successful, statewide MassCARE community.”

After discussing the different activities which take place throughout the year by both sites and consumers, Donna was asked about her goals and challenges for the coming year and how she would like consumers to help MassCARE. Donna first said this seems as though it is a very easy question with long answers (longer than we have for this space). However Donna narrowed her top three goals for the program:

- “1) Increase MassCARE visibility so providers are aware that we are a resource for care, outreach and consumer support,
- 2) strengthen our outreach to women engaged in high-risk behavior, and lastly to
- 3) find out from present FAN members what types of activities they would like to work on with the MassCARE Program such as RFP (request for proposal) review.

Also, I would really like to work with the FAN on specific topics such as teen focused programs, and outreach to young women engaging in risky behaviors to get them back into care.”

During the closing of the interview we talked about the challenges for the MassCARE program

- 1) to monitor trends in the epidemic and respond to them
- 2) to keep reviewing the type of care we provide to make sure that we are meeting the needs of our clients.

Donna concluded by stating, “I look forward to my second Voices Conference and to the opportunities and challenges that this next year will bring.”

Would you like to get MassCARE News?

Name: _____

Address: _____

City, State, Zip: _____

Return to Fernanda Gudino-Valentin
MassCARE
Mass Department of Public Health
180 Beaman St.
West Boylston, MA 01583

We hope you enjoy our newsletter. We welcome
your comments and ideas for future editions.

Contact us via email at
fernanda.gudino-valentin@state.ma.us or by phone
at 508-792-7880 x 2322.

MassCARE News Staff

Editor, Valerie Brown

Asst. Editor, Fernanda Gudino-Valentin

Layout and photography, Hayley Arnett

MassCARE Director, Donna Shecrallah

MassCARE is published by the Bureau of Family
and Community Health, Massachusetts Department
of Public Health, 250 Washington Street, Boston
MA 02108. It is supported in part by project no.
5H12HA0009-08 from the HIV/AIDS Bureau,
Human Resources and Services Administration,
U.S. Department of Health and Human Services.

MassCARE Milestones

MassCARE welcomes **Deborah Gilbert** as the
new Family Support Specialist for the
southeastern region. She will be working in the
Greater New Bedford and Brockton area,
outreaching to women and families. Deborah is a
longtime MassCARE participant – we welcome
her to her new role!

Meliset Garcia, Peer Advocate at Bay State
Medical Center, and **Rosalinda Pedraza** were of
the 20 women chosen from hundreds to attend the
4th National HIV University in San Francisco, CA.
The training, sponsored by WORLD (Women
Organized to Respond to Life Threatening
Diseases) focused on becoming informed about
medical care, dealing effectively with HIV
disease, and training other women in their
community to do the same. This year's training
included workshops on fundraising, using media
in AIDS education, principles of HIV therapy,
long-term management of HIV, building a
treatment education program, and how to do non-
directive treatment education.
Rosalinda and Meliset independently found
funding, and are now in the process of planning an
HIV University for Massachusetts in the spring.
They are looking for 10-15 dedicated women who
might be interested in participating. If you would
like to be a part of this training, contact Meliset at
(413) 794-1651. Look for more on the HIV
University in future MassCARE News.

On October 23, 2000, FAN member Rosalinda
Pedraza was presented with the Duane Draper
Memorial Award. This award is presented each
year to HIV+ people whose work in the
community has improved the quality of life for
people living with HIV/AIDS. Way to go Rosie!

Last spring, FAN participants traveled to
Washington, D.C. for the sixth annual VOICES
2000 conference. While there, they also met with
congressional representatives to educate them on
the HIV issues. The participants were Ann F.,
Maria G., Rosalinda P., Bill H., Luis H., Lenora
F., Regina O., Debbie G., Carl M., Lisa W., and
Candy C. Staff members Fernanda Gudino-
Valentin and Donna Shecrallah also attended.

Clinic and Special Events

Schedule Per Site

Brockton: MassCARE in Brockton is beginning new women's support and art therapy group which will meet Thursday mornings from 10 to 11:30. Art therapist Linda Lufkin will lead projects that help clients use their creativity and express their emotions and experiences.

Other ongoing events include a monthly consumer luncheon and a teen/young adult HIV prevention and education networking group. All groups will be held at BAMSI, 500 Belmont Street, Brockton. Contact Donna Costa at (508) 580-0219 for more information.

Lawrence: Clinic continues to be held the first and third Wednesday of each month at the Greater Lawrence Family Health Center, 34 Haverhill Street, Lawrence. For more information, contact Donna Picard at (978) 689-6731

Lowell: Clinic is held the second Wednesday of the month at Lowell Community Health Center, 585 Merrimack Street, Lowell. contact Donna Picard at (978) 689-6731

New Bedford: Clinic is held the third Thursday of each month from 9 a.m. – 12 noon at the Greater New Bedford Health Center, 874 Purchase Street, New Bedford.

Family Support Group, is a group for primary caretakers of HIV positive children, their children, and their family members. The group meets the second Thursday of the month.

The recently initiated Greater New Bedford Adolescent HIV Networking Group, which is comprised of providers who serve adolescents in the New Bedford community, meets the second Wednesday of each month contact Louise Norko or Libby Robert at (508) 992-6553.

Springfield: Clinic is held in Springfield at 3300 Main Street on Mondays from 9 - 11:30 a.m. and Thursdays from 2 – 5 p.m. Clinic is held in Holyoke at Holyoke Pediatric Associates on the 4th Wednesday of every month at Holyoke. Mother's group meets on the 2nd Wednesday of every month. Teen group meets on the 4th Wednesday of every month. Contact Frances Santiago, R.N. at (413) 794-5014 for further details.

Mark Your Calendar

Ryan White Conference on HIV and AIDS

February 16 – February 19, Denver CO

The Ryan White National Youth Conference on HIV and AIDS (RWNYC) is the only national conference solely dedicated to building the skills of young AIDS activists, youth peer educators, and those who work in support of young people.

HIV Prevention Networking Day for Front Line Service Providers and Peer Advocates

February 28, Worcester, MA Holiday Inn

This is a day-long networking meeting in which participants will hear from national and local prevention programs, meet others working on HIV prevention, learn strategies for getting those at risk into care, and assess their own capacity. Contact the AIDS Bureau of the Massachusetts Department of Public Health, (617)-624-5300, for more information on attending.

VOICES 2001: The National Conference on HIV/AIDS and Children, Youth & Families

May 5 - May 8, Washington, DC

Voices 2001, AIDS Alliance's seventh annual conference, is for anyone who wants to help improve the lives of children, youth, women, and families affected by HIV/AIDS. Participants will include people living with and affected by HIV/AIDS, health care providers, mental health workers, educators, program administrators, researchers, and advocates

MassCARE will again be sponsoring folks to attend this great conference – more details to come on how to apply to attend at FAN meetings. Or, call Fernanda Gudino-Valentin at (508)792-7880 x 2322.

MassCARE Retreat

June 15-17 at Craigville Conference Center on Cape Cod. A great opportunity to meet and share with other parents - watch for more details in future issues.

Family Networking Day

July 21 (rain date on July 28) at same place as last year, Breezy's Park in Douglas, MA, about 30 minutes outside of Worcester. More details to come.

MassCARE
250 Washington Street -4th Floor
Boston, MA 02108
ADDRESS CORRECTION REQUESTED



Nutrition News



By Kathy Cunningham, Special Health Needs Nutritionist MA Department of Public Health

Wasting, a common problem associated with HIV, is unintentional and progressive weight loss. Weight loss is often accompanied by weakness, fever, diarrhea, and nutritional deficiencies, which can diminish the quality of life.

Weight loss in early HIV is commonly related to a loss of appetite due to anxiety and depression. As HIV progresses weight loss can be associated with loss of essential muscle mass and breakdown of multiple organ systems. Currently, the defined causes of HIV progressive wasting are not known, however it is often an imbalance between food choices, total calorie intake and how your body burns those calories. Many approaches have been used to reverse weight loss such as appetite stimulants, which boost your appetite so that you feel the desire to eat foods. These often do plateau out after a period of two weeks. Another approach is steroids, which may increase muscle mass or growth hormone therapy to increase metabolism. The best method to prevent weight loss should involve three areas: appropriate nutrition intervention, increased physical activity and finally pharmacological approaches. The goals of these approaches are to increase body weight and increase body muscle mass.

First Nutritional Counseling with a Dietitian will assist you to develop an appropriate plan to prevent weight loss, increase muscle mass and maintain energy and protein balance to meet their needs. They will maintain a chart to keep track of your body weight and how much of it is fat and muscle. Vitamin and mineral supplements should be discussed as well as a variety of specific foods, and products that can help with the problems related to weight loss.

Second, Physical Activity should be included to strengthen the muscles and improve bone-density. Activities that provide weight-bearing exercises such as weight lifting and walking help retain or increase muscle mass. Coordination of physical activity with nutrition intervention should help with improvement of overall wellness, decrease depression and aid the body to build and strengthen muscle mass.

Third, Pharmacological Approaches may be helpful if nutrition intervention and increased physical activity are not working. Such things as appetite stimulants like dronabinol, megestrol acetate, anabolic agents such as steroids or growth hormones and motility and anti-motility which help regulate bowel function are a few of the approaches to talk with your health care provider about.

Many people living with HIV use complementary and alternative medicines known as CAM. There are a variety of CAM therapies used to increase appetite, and reduce the effects of wasting. If you are using or considering using complementary therapies discuss this with your health care provider.

Therapies that incorporate healthy nutritional practices should be reinforced. However, caregivers and individuals should be cautious about therapies which:

- ◆ Suggest the exclusion of an entire or large number of foods within a food group without replacement from other sources (e.g. macrobiotic diets)
- ◆ Involve unsafe food and water practices (e.g. use of uncooked meats)
- ◆ Are extremely expensive. The cost of the products should not interfere with the ability to maintain appropriate food budget. (e.g. multiple nutritional supplements).

Talk with your healthcare provider if you have specific concerns and to discuss how you can use Nutrition Intervention, Physical Activity and Pharmacological approaches to prevent wasting.

Teen Talk

Alexis Rodriguez is an involved MassCARE participant who agreed to serve as a teen panelist at last year's MassCARE retreat. We asked him to share his thoughts on the retreat and his experiences with us.

Hello! My name is Alexis Gonzalez. Back in 2000 it was an honor for me to be invited to the MassCARE retreat on Cape Cod. It was a great experience for me, especially since this conference was held in an area with wonderful scenery and a close beach nearby. Meeting new people during that trip was also wonderful...and so were the meals that were served. But there was a slight problem...When it was my turn to speak out about my past and current experiences, I was left speechless for most of that time. I sometimes think that I could never handle speaking out in front a crowd of people. But despite that, I was very happy to have gone to that trip.

I would like to share the ups and downs of my experience of being affected with the HIV virus. Now first of all, I considered myself in a normal-healthy family since that's exactly what my childhood experience felt like. But, right when I began to see that my younger sister Daisy Rodriguez began to get seriously ill and then getting taken to the hospital back and fourth, I began to have second thoughts. As time past, Daisy's health got worse. And the next thing I knew, my Mother asked me for a private talk in order to prepare to tell me the heartbreaking news...Daisy was dying!!! I quickly broke down into tears and I just never felt so terrified in my life to hear such a thing. As the day came...I stood there so emotionally paralyzed because watching my little sister lying in her hospital bed lifeless made me feel extremely sad and devastated. I just never thought such a thing would happen to a sibling of mine.

Now my Mother had not told me her cause of death until her funeral was done with. As I heard the word AIDS from her explanation I could have not remembered the last time I felt so shocked. I could have not believed that HIV/AIDS was running in my family. Not to mention hearing that

my little brother and Mother were also infected with it. Each and every day I kept feeling the biggest fear ever: losing them both from their sickness. They seem to be all I have in my life. But, I know that Richie and Mom are doing fine from taking their medication. But I still worry about them getting seriously sick...so I privately pray for them both to stay the way they currently are until they receive the cure someday.

Now, there have been ways for me to cope with the fact that I am affected with the HIV virus. Thanks to the people of MassCARE I was able to do so. They have given me chances to travel out of state to attend organizations and meet peers infected/affected with HIV/AIDS. I had shared my experiences with them and they did the same. At the same time there were fun activities to do. I've traveled to Camp Safe Haven in Martha's Vineyard, the Nationwide Camp Heartland, out of state conferences, and my first ever trip to the MassCARE Retreat in Cape Cod.

Now as I conclude this article, I dedicate it to these following people: Fernanda and Rey, "El Chinito" Luis, Frances, Carlos, Meliset, Maripat, the Director of MassCARE, Donna, and the many other members of MassCARE. Thank you people so much!! I also dedicate this article to the loving memory of Daisy Rodriguez.

Daisy Rodriguez
8/30/83-1/24/94



MassCARE Fathers Group

For several years a group of men involved with MassCARE has been talking about organizing a fathers group. This group would be an extension of our informal conversations about our families while participating in the various MassCARE activities. This desire to have a group became stronger during the annual retreat and other activities. It was during the last retreat that we formalized the steps to have a group. We have been meeting monthly throughout the state since last summer. We meet Sundays between 1:00 and 3:00 p.m.

We have been strengthening this network for mutual support and encouragement in addressing our needs and those of our families. As fathers we are taking greater responsibility in raising our children.

In our meetings we work to create opportunities to deal with HIV prevention and education in our families and communities. We have discussed ways in which racial and class prejudices hurt hopes and lives. We have also talked about fears many men have of homosexuality.

We are fathers of different ethnic and cultural backgrounds. Current members are Latinos, whites, straights and gays. Young adults who assist in the care of siblings and other relatives also participate. Some fathers have the virus while others do not. This blend of fathers from all walks of life has greatly enriched the group. We all respect each other's confidentiality. Now we want you to hear the voices of participants in our group:

"It's a Blessing that I can share with other fathers who are going through the same experience I'm going through. I can get advice as well as give advice"

"I like the group because one exchanges information and is a good support place. We are together in good and bad times. It gives me the hope that I can educate my family, which is positive, in our daily life. The group gives me the strength to continue my life"

"I think that the MassCARE fathers group is going very well for me. I get to share my thoughts with actual fathers as father figure to my little brother."

"When I go to the group I feel I'm among family. I can express myself without fear and trust that I don't have to hide anything. I would like to see fathers who are fearful of speaking out join this group because in our union we find strength."

"This is the only space in which I can be open about what my wife and daughter are going through. I live with this secret. Nobody else in our family knows about it. Friends don't know it either."

"At last we have this group. We are working hard towards the goals we want to accomplish. The group has meant a lot to me because we can share the thoughts and experiences we have. It also gives us the opportunity to bond like brothers and enjoy the company of new families."

As always, we welcome other fathers who are interested in having this experience.

For more information about joining the group please call Fernanda Gudino-Valentin, Coordinator of Family Support Initiatives, at (508) 792-7880 ext. 2322.

